



Family Matters

Elizabeth Ahmann, ScD, RN, and Deborah Dokken, MPA

Transitions from Pediatric to Adult Care: Programs and Resources

Juliette Schlucter, Deborah Dokken, and Elizabeth Ahmann

This article is the third in a series addressing the critical issue of the transition from pediatric to adult care for young adults with complex chronic conditions. Sharing the invaluable perspectives of patients and families, the two previous articles identified key transition needs and challenges, and grounded transition in the principles of patient- and family-centered care. In this final article, a number of exemplary programs and resources for transitioning young adults will be highlighted to help pediatric nurses increase their own awareness of possibilities. The programs are hospital-based and were developed through collaboration between clinicians, patients, and families. Some resources are specific to certain conditions; others relate broadly to young adults with complex or chronic conditions. Please note: These programs and resources do not encompass the totality of what is available to patients and families to support successful transitions.

Programs

The Bristol-Myers Squibb Children's Hospital At Robert Wood Johnson

"My Healthy Transition Toolkit"

- The "My Health Transition Toolkit" supports transition needs of children 12 years and older across all specialties.

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This third article in a series on the critical issue of the transition from pediatric to adult care for young adults with complex chronic conditions offers resources, including information about exemplary programs, to pediatric nurses. Three hospital-based programs are highlighted, four key Internet resources are identified, and five relevant articles are annotated. This information can support pediatric nurses in considering transition support options for individual teens and their families as well as in developing resources and designing programs in their own settings.

- The Family Advisory Council (FAC) of Bristol-Myers Squibb Children's Hospital developed the toolkit under the guidance and leadership of its Family-Centered Care Coordinator.
- In 2012, the FAC began assessing what was available nationally for patients transitioning to adult care and their families.
- The Family-Centered Care Coordinator also implemented a transition readiness survey for patients 12 years of age and older across all specialties.
 1. The survey assessed aspects of self-management, including whether adolescents:
 - Are involved in care management decision-making.
 - Carry their own insurance cards.
 - Make their own appointments.
 - Manage prescription refills.
 2. Results showed that generally adolescents were not learning skills to manage their own health.
- The "My Healthy Transition Toolkit" was designed to include:
 1. Collecting your personal health information: immunization records, medication lists, test results and hospitalization summaries, important phone numbers.
 2. Communication logs and summaries of important conversations with the health care team.
 3. Inventory and checklists about health care equipment and supplies.
 4. Healthy eating checklists.

The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Elizabeth Ahmann, ScD, RN; Series Editor, or Deborah Dokken, MPA, Series Editor; *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

5. Explanations of HIPAA and advance directives.
6. Transition tips.
7. Tips for teens choosing a doctor and tips for talking to your doctor.
8. Encouragement to customize the toolkit and information collected to keep it relevant.
9. Online resources.

Since implemented, use of the Toolkit has expanded to encourage healthy teens in developing independence in healthcare self-management.

For additional information:

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The Children's Hospital of Philadelphia (CHOP) "REACH": Rapport, Empowerment, Advocacy, through Connections and Health

- The REACH program provides transition guidelines, retreats, and support for health care professionals, teens, young adults, and their families.
- CHOP's Director of Community Education developed and implemented the program in partnership with young adults.
- To identify the types of resources that would be most effective in supporting transitions, the REACH program collaborated with the CHOP-Penn Transition Program for Digestive, Liver and Pancreatic Medicine to host focus groups with clinicians, young patients, and their families preparing for transition and those who recently transitioned to adult care. A video from each of these perspectives is available online at: <http://chop.edu/video/gi-patients-moving-adult-healthcare-introduction>
- REACH includes:
 1. Resources for patients and their families, including checklists and tips that focus on self-care and self-advocacy.
 2. A guide for health care professionals with:
 - A step by step checklist for transitioning care.
 - Tips for introducing health care independence as a process, not a one-time event.
 - A focus on the changing relationships in health care as adolescents reach young adulthood and begin to speak alone and confidentially with their health care team.
 3. Workshops for youth that focus on skill development, coaching, and empowerment.
- REACH resources focus on youth with chronic illness 11 to 24 years of age and include information for caregivers about setting the stage as early as 4 years of age for the shared objective of health care independence.
- In collaboration with REACH, several programs and divisions at CHOP are providing focused attention on customized logistics and resources for the specific needs of individual patient populations.
- "Career Path" is a program component providing evaluation and internships at CHOP or in the community to bridge the gap between high school and the work world. Over 30 Career Path graduates work at CHOP.

An unexpected benefit of the program includes gains in participant self-management of health care.

For additional information:

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The NYU Langone Medical Center Division Of Pediatric Neurosurgery

"The Healthy Transitions Program"

- "The Healthy Transitions Program" includes both a transition workshop for young people and parents, and written information focused on the transition process.
- The Social Worker of the Division of Pediatric Neurosurgery at the NYU Langone Medical Center partnered with clinicians, young patients, and families to develop the Healthy Transitions Program.
- Hallmarks of the program include:
 1. Encouraging young patients to begin taking more responsibility for their health care as early as 12 or 14 years of age.
 2. Networking opportunities for teens and parents to meet others who are on the same journey or have recently transitioned to an adult care model.
 3. A focus on young adult self-management, including access to the medical record, medication management, explanation of insurance jargon, forms, and coverage overview.
- Workshops support patients and parents:
 1. Teens work with staff on competencies including:
 - Scheduling their own medical appointments.
 - Arranging for transportation when needed.
 - Health literacy surrounding individual diagnoses.
 - What to do to stay healthy.
 - Awareness of symptoms.
 - Understanding what defines an emergency and how to respond.
 - Ability to tell health care providers how one feels.
 - Answering health care providers questions.
 - Asking health care providers questions about their condition.
 - Obtaining medical records when needed (portable medical record).
 2. Parents learn both what to expect and how to support and coach their children in increasing self-management of their health care.
- All transition materials are translated into Spanish and other key languages to support the diverse needs of the patients and families.

For additional information:

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Online Resources

Adolescent Health Transition Project (AHTP)

The Adolescent Health Transition Project of the University of Washington, funded by the Washington State Department of Health, Children with Special Health Care Needs Program, developed this website with a variety of resources, including a video, Transition Planning Guide, Health History Summary, and Health Care Skills Checklist. <http://depts.washington.edu/healthtr/resources/tools.html>

Got Transition/Center for Health Care Transition

The "Got Transition" website is a cooperative arrangement between the Maternal and Child Health Bureau, The National Alliance to Advance Adolescent Health, and other partners. It offers a variety of tools (in English and Spanish) organized by six core elements of health care transition.

<http://www.gottransition.org/resources/index.cfm>

Healthy Transitions NY

This website was developed for youth with developmental disabilities 14 to 25 years of age, family caregivers, service coordinators, and health care providers. It provides tools for care coordination, keeping a health summary, and setting priorities during the transition process.

<http://www.healthytransitionsny.org>

National Diabetes Education Program (NDEP)

To help teens with diabetes make a smooth transition to adult health care, NDEP has assembled a variety of materials, including a transition planning checklist, health status summary, and links to other resources.

<http://ndep.nih.gov/transitions/index.aspx>

Reading

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. (2011). *Pediatrics*, 128(1), 182-200. doi:10.1542/peds.2011-0969 <http://pediatrics.aappublications.org/content/128/1/182.full>

From the Abstract: "This clinical report represents expert opinion and consensus on the practice-based implementation of transition for all youth beginning in early adolescence. It provides a structure [including a decision-making algorithm, age-specific guidelines, and attention to provider, family, and youth readiness, including youth with special health care needs] for training and continuing education to further understanding of the nature of adolescent transition and how best to support it. [Health care providers]...are encouraged to adopt these materials and make this process specific to their settings and populations."

Current Status of Transition Preparation among Youth with Special Needs in the United States

McManus, M.A., Pollack, L.R., Cooley, W.C., McAllister, J.W., Lotstein, D., Strickland, B., & Mann, M.Y. (2013). *Pediatrics*, 131(6), 1090-1097. doi:10.1542/peds.2012-3050 <http://pediatrics.aappublications.org/content/131/6/1090.long>

From the Abstract: This summary of the 2009-2010 National Survey of Children with Special Health Care Needs explains that "[T]here have been no discernible improvements since this transition outcome was measured in...2005-2006..." "Most [60%] YSHCN are not receiving needed transition preparation. Although most providers are encouraging YSHCN to assume responsibility for their own health, far fewer are discussing transfer to an adult provider and insurance continuity. [The analysis also shows that transition preparation is less likely for males; blacks and Hispanics; those with lower incomes; those with disabilities; those with mental, behavioral, or developmental conditions;...and those lacking insurance coverage (p. 1094), and that the medical home "substantially increases the odds of having transition discussions" (p.1096).]

Diabetes Care for Emerging Adults: Recommendations for Transition from Pediatric to Adult Diabetes Care Systems

Peters, A., Laffel, L., & the American Diabetes Association Transitions Working Group. (2011). *Diabetes Care*, 34(11), 2477-2485. doi:10.2337/dc11-1723 <http://care.diabetesjournals.org/content/34/11/2477.full.pdf+html>

From the Abstract: "For emerging young adults with diabetes, it is particularly important to create effective and translatable processes for the transition in care from pediatric to adult providers in order to optimize well-being and health for the near term. It is additionally imperative for these young adults to achieve target glycemic control in order to prevent long-term complications and to maximize lifelong functioning" (p. 2483). This position statement identifies transition issues, including differences between pediatric and adult care, poor control of glycemia and other risk factors, loss to follow up, increased risk for complications, psychosocial issues, sexual and reproductive issues, alcohol, smoking and drug abuse, and chronic diabetes complications. Additionally, 14 evidence-based recommendations for care transition are detailed in the text.

Cystic Fibrosis and Transition To Adult Medical Care

Tuchman, L.K., Schwartz, L.A., Sawicki, G.S., & Britto, M.T. (2010). *Pediatrics*, 125(3), 566-573. doi:10.1542/peds.2009-2791 <http://pediatrics.aappublications.org/content/125/3/566.long>

From the Abstract: "Transition of young adults with cystic fibrosis (CF) from pediatric to adult medical care is an important priority because many patients are living well into their fourth decade... This state-of-the-art review...provide[s] context for the scope of the challenges associated with designing and evaluating health care transition for adolescents and young adults with CF and implications for all youth with special health care needs."

Transitioning from Pediatric To Adult Health Care

Harris, M.A., Freeman, K.A., & Duke, D.C. (2011). *American Journal of Lifestyle Medicine*, 5(1), 85-91. <http://www.medscape.com/viewarticle/738852>

From the Abstract: "Although recognition of the issues and problems of transition has increased during the past decade, meaningful systematic changes have not occurred. [In this article], [t]he challenges of transition are systematically presented and organized by patient, family, pediatric treatment team, adult treatment team, and institutional and system issues. Recommendations are provided for each of these areas, beginning with an emphasis on institutional and health care systems policy revisions that are a foundational and necessary element to build meaningful change. In addition, recommendations are provided...specific to pediatric and adult health care teams, as well as patients and families."

Closing

With advances in medicine, a growing number of children with complex or chronic medical conditions are reaching the age of young adulthood and must transition from pediatric to adult providers and settings of care. Unfortunately, the transition is often difficult, as the stories of patients and families in this series of articles have highlighted. Not only do patients and families feel frustrated and abandoned, but at times, care is compromised as well. Fortunately, this issue of transition in care has gained attention – from the Maternal Child Health Bureau and the American Academy of Pediatrics to individual hospitals and health systems. Still, much more needs to be done. Pediatric nurses have a critical role to play – both in working with individual patients and families, and in helping develop programs that will improve the transition process for teens and young adults into adult care. ■